

# THE 2015 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: RECOMMENDATIONS AND ACTIVITIES

Pursuant to Code of Virginia § 51.5-154, the Virginia Alzheimer's Disease and Related Disorders Commission (Commission) must submit to the Governor, General Assembly, and Department for Aging and Rehabilitative Services (DARS) a report regarding the recommendations and activities of the Commission. The Commission, chaired by Courtney Tierney, develops and oversees the implementation of the Commonwealth's plan for meeting the needs of individuals with Alzheimer's disease and related disorders and their caregivers.

## VIRGINIA DEMENTIA STATE PLAN 2015-2019

In December 2011, the Commission released the first *Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and their Caregivers*. In spring 2015, the Commission engaged individuals with dementia, their caregivers and other stakeholders across Virginia at five public listening sessions and received invaluable input for the revised plan. The updated plan includes a new focus on coordinated care through a network of memory assessment clinics and increased focus on connections to public health initiatives. The plan guides legislators, other public officials, health and human services professionals, advocates, and other interested people on best practices and specific strategies for dementia-focused data collection, care, training, and research.

The five goals of the Virginia Dementia State Plan are:

1. Coordinate quality dementia services to ensure a dementia-capability,
2. Use dementia-related data to improve public health,
3. Increase awareness and create dementia-specific training,
4. Provide access to quality coordinated care in the most integrated setting, and
5. Expand resources for translational research and evidence-based practices.

Virginia's Dementia State Plan, working in tandem with the National Alzheimer's Plan, provides the best chance of responding to dementia and providing support to the estimated 130,000 Virginians with Alzheimer's disease.

## COMMISSION RECOMMENDATIONS FOR 2016 GENERAL ASSEMBLY

The 2015 General Assembly recognized the Commission's proven track record of advocacy and provided funding for Alzheimer's training for first responders and public guardianship. Acting in its advisory capacity and to further the Dementia State Plan goals, the Commission recommends the following actions to effectively and efficiently serve individuals with Alzheimer's disease and other dementias and their caregivers.

Develop and Fund  
Interdisciplinary  
Memory Assessment  
Clinics with Dementia  
Care Managers

Revise Code Language on  
Informed Consent for  
Research Involving  
Individuals with Cognitive  
Impairment

Implement Discharge  
Screenings for Virginia  
Residents in Out-of-State  
Hospitals In Need of  
Waiver Services

## DEMENTIA STATE PLAN 2014-2015 ACCOMPLISHMENTS

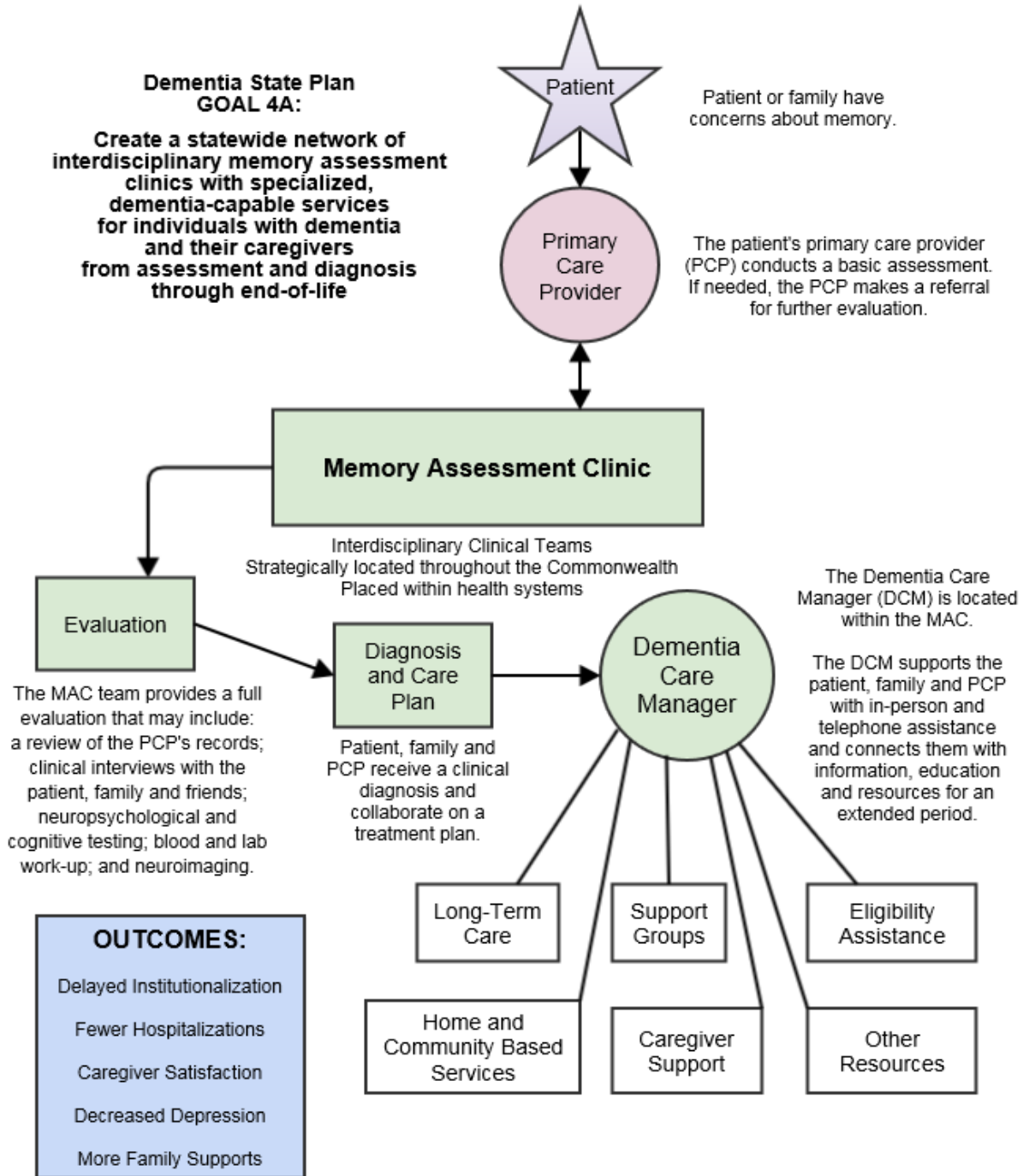
**DATA AND RESEARCH:** In 2015, Virginia is collecting important data on memory loss and caregiver stress through the annual public health Behavioral Risk Factor Surveillance System Survey using the Caregiver and Cognitive Decline Modules.

**TRAINING:** Virginia allocated \$50,000 for first responder training on Alzheimer's and dementias. Virginia received a three-year, federal grant to advance the dementia-capability of the aging network and to implement caregiver and family counseling in the greater Charlottesville and Williamsburg regions.

**COORDINATED CARE:** Virginia amended the Alzheimer's Assisted Living Waiver regulation definition to include other related dementias effective September 9, 2015. The Commission expanded on its listing of interdisciplinary memory assessment clinics, available on [www.AlzPossible.org](http://www.AlzPossible.org).

# Develop and Fund Interdisciplinary Memory Assessment Clinics with Dementia Care Managers

The Alzheimer's Association (2015) estimates that only 45% of people with Alzheimer's disease or their caregivers report being told of their diagnosis. Further studies have found that primary care providers are often overwhelmed, ill-equipped, and under-resourced to provide comprehensive management or care coordination for individuals with dementia. Coordinated care programs using trained Dementia Care Managers embedded in the memory assessment clinics are desperately needed for successful dementia-specific care and would realize significant cost savings, decrease health care utilization, and improve health outcomes. By providing an early, specific diagnosis to patients, the interdisciplinary clinic teams can pave the way for essential wrap-around supportive services, including the delivery of early-stage clinical and social intervention approaches, education on the disease progression and behavior management techniques, referrals to available quality and affordable services, and the development of advance directives.



## Revise Code Language on Informed Consent for Research Involving Individuals with Cognitive Impairment

Code of Virginia § 32.1-162.18 requires informed consent for human research in the Commonwealth.

The Commission calls for a statutory revision to the informed consent for human research provision. Language was placed in the Virginia Code that allows persons with dementia to be involved in human research when legally authorized representatives provide consent on their behalf. Researchers report that the antiquated terminology used for disease conditions and human research has not kept pace with the science. Certain phraseology needs technical clarification to ensure that research for prevention and treatment for dementias continues unimpeded.

## Implement Discharge Screenings for Virginia Residents in Out-of-State Hospitals In Need of Waiver Services

The Dementia State Plan hearings in far southwest Virginia revealed a serious problem regarding Uniform Assessment Instrument (UAI) screenings for Virginia residents upon discharge from a hospital in a neighboring state.

Over 100 Virginians attended the public listening sessions for the Dementia State Plan update, which were conducted in partnership with the four chapters of the Alzheimer's Association serving Virginia and Mountain Empire Older Citizens in Big Stone Gap. In Big Stone Gap, it is not uncommon for residents to seek acute care treatment in an out-of-state hospital, which may be closer than an in-state hospital. At the listening session in Big Stone Gap, family caregivers and professionals highlighted the region's problems getting a Uniform Assessment Instrument (UAI) screening for a Virginia resident needing a waiver placement when the resident was being discharged back into his or her Virginia community from an out-of-state hospital. The Commission will work with the state and local agencies involved to resolve the jurisdictional issues and streamline access to services over the coming year.

### COMMISSION ACTIVITIES

**Dementia Care Best Practices:** In 2014, Delegate Orrock asked DARS to do a study of dementia care “best practices” in the Commonwealth and ways to expand and encourage such practices across all levels of care and settings with a final report date of October 1, 2014. Charlotte Arbogast, MSG, Virginia's first Dementia Services Coordinator (DSC) at DARS, served as lead on the Best Practices study. On January 27, 2015, she joined Delegates Mark Keam and Steve Landes at a press conference with dementia care stakeholders to present the report. Persons may contact the DSC and review a copy of the report through [www.AlzPossible.org](http://www.AlzPossible.org).

**AlzPossible:** The Commission, in collaboration with the Virginia Commonwealth University Department of Gerontology and World Events Forum, Inc., maintains the AlzPossible website. Aimed at providing professional caregivers in Virginia updated information on dementias, the innovative AlzPossible site hosts:

- The Commonwealth's Dementia State Plan,
- A library of free webinars for professionals and caregivers on dementias and related topics,
- A map and listing of interdisciplinary memory assessment centers in Virginia to guide consumers to clinics that provide thorough and holistic diagnostic and treatment services for memory disorders,
- Information and links to available data sets for researchers in Virginia interested in dementia,
- Links to local, state, and national resources, including state agencies, Senior Navigator, the Alzheimer's Association, and the federal ElderCare Locator and Alzheimers.gov.

### CURRENT FOCUS

The Commission continues to partner with public and private partners throughout Virginia and at the national level to implement the Dementia State Plan. In the 2016 General Assembly session, the Commission will promote its recommendations for expanded support for people with dementias and their caregivers and facilitating dementia research and access to services. Additional information about the Commission may be found at: <http://www.vda.virginia.gov/alzcommission.asp>.